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Rezension : Transhumanist Dreams and Dystopian Nightmares: The Promises and Peril of Genetic Engineering

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DOI: <https://doi.org/10.1007/s11019-012-9453-1>

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ZORA URL: <https://doi.org/10.5167/uzh-67712>

Journal Article

Published Version

Originally published at:

Roduit, Johann A R (2013). Rezension : Transhumanist Dreams and Dystopian Nightmares: The Promises and Peril of Genetic Engineering. *Medicine, Health Care and Philosophy*, 16(1):116-117.

DOI: <https://doi.org/10.1007/s11019-012-9453-1>

Short literature notices

Roberto Andorno

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Chadwick, R., ten Have, H., Meslin, E. M. (eds.): 2011, *The SAGE Handbook of Health Care Ethics*. London: SAGE Publications. 454 pp. ISBN: 978-1-4129-4534-9. Price: £95.

Since the first appearance of the expression ‘bioethics’ in the works of the American cancer specialist Van Rensselaer Potter, bioethics has continued to be a field of controversy and a *topos* of academic debate. On the one hand, it attempts, with a truly interdisciplinary approach, to harmonize the knowledge of biology, the science of living systems, with the different value systems that have developed throughout the history of humankind. This attempt continues to cause difficulties for both scientists and philosophers, for a variety of reasons. On the other hand, bioethics itself is questioned and criticized as to whether it is an independent scientific field of inquiry at all in the field of applied ethics and philosophy.

Similarly under debate is the term ‘bioethics’. Potter’s concept of bioethics challenged the term ‘medical ethics’. His definition expanded bioethics to include, along with issues of medicine, life sciences, and new technologies also environmental issues, questions of population, peace, pollution, poverty, politics and progress. However, the emergence of health care professions (nursing, social work, pharmacy, etc.), and their own independent professional ethical standards, encouraged the editors of this *Handbook* to rather use the term ‘health care ethics’. They do so, while recognizing the impreciseness of this term and

despite the fact that both bioethics and health care ethics are frequently used as interchangeable terms.

The editors of the *Handbook*, in a successful attempt to provide a comprehensive overview, have decided to touch upon five key topics currently debated in health care ethics: (1) theoretical perspectives (methodology of ethics; foundationalism and principles in ethics; criticism from anti-theory movements), (2) traditional areas of bioethics (reproductive health care; end of life issues; human rights and professional codes of conduct), (3) vulnerability of groups (mental health; children; orphan diseases; poverty), (4) research ethics (global context; international research), and finally (5) emerging technologies (gene therapy and stem cell research; screening; telemedicine; brain death and organ transplantation; nanotechnology; environmental health; pharmaceuticals).

All the chapters provide a high-level and state-of-the-art presentation of these particular topics in their various fields of health care ethics. However, one should not forget the original intention of the editors of this *Handbook*, which was to shift the definition of bioethics to *global bioethics*. Indeed, all the developments in health care ethics, including the already present ethical problems and relevant ethical principles or newly emerged ethical issues, are becoming eminently international. As ethical reflection incorporates increasing awareness of sociological, religious and cultural differences, bioethics also increasingly reflects the global scene: the distribution of scarce health care resources, health research in different continents, standardization of ethical guidelines alongside with biobank data-sharing, just to mention a few. We have all witnessed the subtle transition of the predominantly individualistic and autonomy-based approach of bioethics, towards a more public health-oriented approach, reflecting health inequalities *between* instead of *within* societies. As global

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bioethics does not deal with particular groups, but is more concerned with institutional and political backgrounds, it puts an special emphasis on issues of justice. The editors highlight the need to not only focus during the analysis on cultural, social and religious moral differences, but also to focus on discovering common standards, which we all share as human beings (although not ignoring the differences either). One milestone on the road towards the development of *global bioethics*, according to the authors, is the UNESCO *Universal Declaration on Bioethics and Human Rights* (2005). This corresponds with Potter's initial idea of bioethics; an idea that bridges nature and culture, putting humankind and its environment into a perpetually complementary relationship.

The SAGE Handbook of Health Care Ethics, with chapters from eminent authors in their field, such as Henk ten Have, Roberto Andorno, Diego Gracia, Paul Schotsmans, Ruth Chadwick, Bert Gordijn, and Kris Dierickx, just to mention a few, provides the reader with an accurate and fascinating ethical analysis of different health care ethical issues. Anyone keen to learn and understand more about bioethics, global bioethics, and the key issues and debates in this field, would do well to consult and read this valuable publication.

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Mehlman, M. J.: 2011, *Transhumanist Dreams and Dystopian Nightmares: The Promises and Peril of Genetic Engineering*. Baltimore, MD: The John Hopkins University Press. 288 pp. ISBN: 978-1421406695. Price USD \$29.95

In *Transhumanist Dreams and Dystopian Nightmares*, Maxwell J. Mehlman, Professor of Law and of Bioethics at Case Western Reserve University in Cleveland, Ohio, exposes some of the risks and benefits of genetic engineering. What will happen when we enter the age of "engineering evolution", when the evolution of our species will be guided by genetic engineering? He writes, "Whether scientists are dubious or optimistic about the prospects for rational evolution, though, they tend to agree on two things. First, however long it will take to perfect the necessary technology, it is inevitable that humans will attempt to control their evolutionary future, and second, in the process of learning how to direct human evolution, we are bound to make mistakes. This book is about these mistakes" (7–8). Mehlman proceeds in three parts. He first outlines two antagonistic visions of the future, then raises some problems with genetic engineering, and finally gives advice on how to manage risks.

In the first chapter, Mehlman contrasts the transhumanist vision of the future, where bliss, immortality and youthfulness are promised, with a dystopian vision of the future

where the genetically modified individuals would be exploited, discriminated and suffering. He then outlines how scientific research has already caused a great amount of fear in the past (chapter 2), and wonders what we can learn from these experiences. From chapter three to seven, the book outlines some problems that need to be anticipated when considering "engineering evolution". After looking at the physical (chapter 3) and nonphysical possible harm (chapter 4), the author looks at consequences for society (chapter 5) and what aspect of "engineering evolution" might be a threat to our own species (chapter 6). Additionally, the lack of understanding about 'natural' evolution complicates making engineering evolution safe (chapter 7). The last part of the book is about how to manage the risks of genetic engineering and protecting our children (chapter 8), social cohesion (chapter 9), our descendants (chapter 10), and the human species itself (chapter 11).

Two points merit further attention. First, Melham argues that it is inevitable for society to put their trust in experts when considering how to engineer humankind. He writes, "Lawyers and other lay regulators are going to have to continue to rely on scientific experts ... where the science is so complex that it may be comprehensible, if at all, only to the researchers themselves" (42). I find it unsatisfying that the 'fate of humanity', so to speak, will be in the hand of a selected few experts or elite. In contrast, French psychoanalyst Roland Gori recently mentioned in a documentary aired by the French–German Channel ARTE that "we have to renounce to leave it to experts to guide our lives (...); we must be able to claim back the democracy that we have tended to abandon to them" (See "Un monde sans humains?", available on YouTube). Mehlman continues "The best that can be hoped for is that the nonscientists maintain a firm skepticism, learn how to distinguish reliable scientific informants from quacks, have the humility to admit when they are confounded, and press relentlessly until they obtain the necessary answers" (42). When the price is the fate of humanity itself, we need to ensure that science is grounded ethically, because following scientific progress without ethical reflection might lead us to a dystopian nightmare.

Second, Mehlman calls us to pause and deeply think about what we are about to do (110), because the fate of humanity is at stake. He writes, "Our descendants will encounter many great challenges ... Yet humanity faces a great test now as well. Rather than just passing genes on to our offspring the way those before us did, we are acquiring the technological wherewithal to reconstruct those genes. If we botch it, children will suffer, the lineage might die out, and that will be that. If we succeed, we will earn the gratitude of our descendants" (230). While some might be skeptical because some scenarios outlined in the book

sound like science fiction, it is important, in my opinion, that we take time to reflect about a rapidly evolving technology. We need ethics that guide science, and not a science that guides ethics.

In summary, when facing such great threats and promises, it is crucial that we *pause* and reflect on it, while encouraging a more democratic discussion. To do so is extremely difficult, because as Melham points out, we are in a sense already in the age of engineering evolution, with technologies such as In vitro fertilization (IVF) and pre-implantation genetic diagnosis (PGD) (2–3). This book is a right place to start our reflection. It would be an excellent read for geneticists, futurists and ethicists. But I would encourage every citizen to have a grasp of these issues, as the utopia exposed in *Transhumanist Dreams and Dystopian Nightmares* might well be the utopia of this century, if not this millennium.

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Simonsen, S.: 2012, *Acceptable risk in biomedical research. European perspectives*. London: Springer, 293 pp. ISBN-978-94-007-2677-2. Price: € 106,95

How much risk and burden is acceptable in biomedical research? This is the key question in Sigmund Simonsen's recent book published by Springer. The volume is based on a theoretical study which is part of his PhD thesis and some of the results from an empirical study to be published elsewhere.

Simonsen addresses the question of acceptable risk from the perspective of European regulations of biomedical research. In particular, he finds the basis of his answer in Article 6 of the Council of Europe's Additional Protocol to the Oviedo Convention concerning Biomedical Research and in Article 3 of the Clinical Trials Directive of the European Union. Here he identifies a principle of requirement of proportionality, which he argues is one of the core norm in biomedical research (together with informed consent), and which is able to operationalize the principle of human primacy at the core of European research regulation.

The origin of the principle of requirement of proportionality is found in the Nuremberg Code, in human rights law, in the Declaration of Helsinki, and in the above mentioned European regulations. The function of the "principle of proportionality" is to protect research participants, to promote trust in research, to balance the interests of science and society and the interests of individuals, to "facilitate justifiable research and scientific progress in biomedicine," as well as to provide a common regulatory standard for research in European countries.

For therapeutic research, where persons may benefit directly from the research (according to "the main rule of direct benefit"), there are in principle no limits to the risks

and burdens a person may be exposed to, as long as the potential benefit is proportional. Nevertheless, Simonsen acknowledges that one should be more careful for persons who are not able to consent.

For non-therapeutic research, where the research person will not benefit from the research but where others may benefit, there are restrictions to the risks and burdens. If the person is able to consent, the risk and burden has to be "acceptable". However, if the person is not able to consent or is vulnerable, only "minimal" risks and burdens are acceptable. Based on a literature review, Simonsen gives plausible interpretations of what "acceptable" and "minimal" risks and burdens are. E.g., a "minimal risk" for death is 1:500,000. He also points out that the assessment of acceptable risk and of proportionality with potential benefits cannot be based on quantitative data alone. They have to be supplemented with qualitative data as well as subjective assessment. He specifically mentions the importance of assessing the PI's competence.

Hence, the "principle of proportionality" is paternalistic, as it sets limits to people's liberty to be exposed to risks and burdens. Simonsen justifies this by the researcher's duty of care. Moreover, the protective intention of the "principle of proportionality" makes it a kind of precautionary principle.

Most interestingly, Simonsen provides a definition of the controversial equipoise principle based on proportionality: "Equipoise" basically means that the risk–benefit ratio of research participation roughly *equals* the risk–benefit ratio of available alternatives." (p. 137).

Simonsen's account is pragmatic and emphasizes the responsibility of the researcher. He uses a series of interesting examples to make his point. Most of the examples and cases stem from Norway, but some are from other countries, e.g., from the USA. He also underscores his arguments by the results from his observational study. He uncovers weaknesses in the European regulation of research, in the Norwegian legislation (where he himself has been one of the main architects), as well as in the National and Regional Ethics Committees.

It can be argued that Simonsen has an overly monothetic interpretation and application of "the principle of proportionality", and that the book lacks a thorough discussion of its normative basis and its relationship to other relevant principles in research regulation relating to risk assessment. Despite "the principle of proportionality's", weighting risks and burdens against potential benefits, Simonsen argues that: "[t]he principle is not an utilitarian principle, but rather a paternalistic principle aimed at protecting the individual (the few) against undue exploitation by society and science (the many), while at the same time facilitating autonomy, altruism, and sound research." (p. 266).

The results from the empirical observational study are both interesting and relevant, but as the methodology and

the premises as well as the limitations of the study are not presented in the book, it is difficult to assess its validity.

Despite these and other objections, I can easily recommend reading *Acceptable Risk in Biomedical Research*. It gives a good overview of European research regulation in general, and the assessment of risk and burden in particular. It is both actual and concrete in its recommendations. Furthermore, it is critical, well structured, and well written. Hence, it should reach a broader audience than only scholars of research ethics and research legislation.

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Gunnarson, M. and Svenaeus, F. (eds): 2012, *The Body as Gift, Resource and Commodity. Exchanging Organs, Tissues, and Cells in the 21st Century*. Stockholm: Södertörns högskola. 400 pages. ISBN 978-91-86069-49-0. Price: unknown.

This book is the result of a research project at the Centre for Studies in Practical Knowledge from the University of Södertörn, in Sweden. The main purpose of the volume is to present and analyse the more important aspects of the debate on organ transplantation and organ trade. The contemporary thinking about organs donation is explained through the use of three metaphors: organ as a gift, as a resource, and as a commodity.

The monograph is divided into eleven chapters, written by thirteen authors from different fields of knowledge; some of them are philosophers, other ethnologists and some others physicians. The research consequently assumes a very multifaceted and complete analysis of the theme. The perspective used by them is traceable to a phenomenological approach.

The first chapter “With Levinas against Levinas” is written by Kristin Zeiler, who examines the implication of a phenomenological ethics, inspired on Levinas. She distinguishes three major strands of the phenomenological ethics, examines Levinas’s ethical thought and embodied subjectivity and tries to analyze the questions relating to the role of embodiment in the Levinasian ethics.

The second chapter, entitled “The Phenomenology of Organ Transplantation”, by Fredrik Svenaeus, who focuses the attention on the relation between organ transplantation and the concept of Identity. He points out a change in the self-perception in individuals who have undergone an organ transplant. The multilayered phenomenology nature of the self is narrated by the personal experiences of three organs recipients; through their testimonies, the author wants to remark the different perception on receiving different organs, which in the case in question are brain, heart and kidney, as consequence of cultural paradigms.

In the third chapter, the anthropologist Aivita Putnina shows the close relation between persons and their bodies.

Body is not only a universal exchangeable of units; in fact it concerns the relations with its social history. The author wants to underline how the uses of biotechnologies, in the case of organ and cell transplantations, have a strong impact on the perception of a unified body.

The fourth chapter (“Concealed by the ‘Gift of Life’”) is written by Martin Gunnarson, who treats to unsettle the common conception of dialysis as a suffering and dying life, in opposition to a view of transplantation as a problem resolving. The author’s position is supported by the experiences reported by patients who came back on dialysis after receiving organ transplantations.

In the fifth chapter, entitled “Utility, Trust, and Rights in Swedish Governmental and Expert Discourses on Organ Donation Policy”, Ulla Ekstrom von Essen, highlighting the contradictory definition of death in Sweden, claims the idea that a ‘dead body’ is seen too many times as a biological resource for potential recipients. The author analyzes what the concept of a ‘right to donate’ implies, basing her assumption on the Swedish utilitarian model.

In the sixth article (“The Body as a Societal Resource in Transnational Giving”), Markus Idvall explores the values of kidneys transplants as a resource in transnational contexts. The example is offered by two organ-exchange organizations, *Balttransplant* and *Scandiatransplant*.

The eighth chapter, entitled “Shifting Responsibilities of Giving and Taking Organs?”, explores the complex concept of ‘responsibility’ in organ donation and trade. The two authors, Mark Schweda and Silke Schicktanz, want to point out how this concept is related to a responsible subject, not only with a moral obligation of a donor.

In the ninth chapter (“Reproductive Labour Arbitrage”), Catherine Waldbe leaves aside the theme of organ donation donations to focus on the contemporary human reproductive market. The analysis principally deals with the ‘fertility tourism’ in the European oocytes market. In the tenth chapter entitled “Trading Hair, Trading Cadaver Tissue”, Erik Malmqvist uses the comparison between Hindu Pilgrim’s hair trade and tissue transplantation from deceased donors to demonstrate that the difference in the two forms of ‘bodily commodification’ does not concern the body parts gone away for trade, but the different motivation on giving them. Following a Kantian point of view, the author disagrees with both of the practices since the assumption is that the body, in all its parts, is constitutive of personhood.

The last chapter (“I had to leave”) is written by the ethnologists Sara Bergund and Susanne Lundin who, beginning with the description of the Swedish kidneys transplantation context, give voice to the personal experience of three respondents resident in Sweden, who decided to circumvent the long transplantation waiting list in the country, having a kidney transplantation abroad. According

to the authors, the motivations used by the recipients to justify their action are explained by three narrative arguments. The first, the existential, that can be summarized as “I did it because I did not want to die”, the second, the normality, which is a concept culturally constructed and related to the social, political and moral order and the third, the discrimination argument, that highlight the feeling of alienation perceived by the three migrants recipients as results of a supposed prejudice.

In sum, the interesting and recurring issue addressed in the book is the instrumental value that organs assume within the market economy. Finally, it is worth mentioning that the volume is freely online available at: <http://sh.diva-portal.org/smash/get/diva2:510121/FULLTEXT01>

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Garrett, J. R. (ed.): 2012, *The Ethics of Animal Research: Exploring the Controversy*. Cambridge, Mass: The MIT Press. 356 pp. ISBN 978-0-262-51691-4. Price: \$ 27.

Over the last 35 years, invasive animal research has become a much debated subject from an ethical and scientific point of view. Given that animal research imposes considerable harm on animals, two main topics need to be addressed: First, compelling evidence for the benefits resulting from animal research should be presented. Second, if there are benefits, we need to ask how invasive research with animals can be legitimate when we refrain from undertaking it in the case of human beings. The main aim of *The Ethics of Animal Research: Exploring the Controversy*, edited by Jeremy R. Garrett, is to present answers to these two questions. In the anthology, four key areas are assessed, and 16 articles offer arguments for and against the ethical permissibility of invasive animal research.

The first part of the book addresses some ethical and scientific starting points. Bernard Rollin offers explanations why the ethics of animal research has been ignored by scientists for such a long time. Stephen Schiffer discusses whether animal research can be justified on the basis of evolutionary principles. He concludes that animal models indeed provide useful insights for humans.

The second part of the book contains six excellent contributions by moral philosophers about the ethics of animal research. Baruch A. Brody analyses the validity of some arguments in favour of animal research, while Alastair Norcross addresses the problem of ‘marginal case human beings’. The other four contributions discuss animal experimentation from a utilitarian (Robert Bass), an animal rights (Tom Regan), virtue ethics (Garrett Merriam) and contractarian (Mark Rowlands) point of view.

The third part of the book is devoted to problems concerning animal research in an era of biotechnology. David

B. Resnik discusses ethical issues concerning transgenic animals in biomedical research, while Autumn Fiester presents an evaluation of animal biotechnology using the method of bioethical casuistry.

The fourth and last part of the book discusses alternative paths concerning the moral permissibility of animal research. Andrew Rowan debates the value of animal research and concludes that we need to refine the techniques that measure its costs and benefits. Mylan Engel searches for a common sense argument against animal experimentation, while Nathan Nobis impressively argues that we do not need new moral theories but rather better logical skills for the rational evaluation of moral arguments. Tom Regan addresses the question whether it is hypocritical of animal rights advocates to use medication available following animal research. Finally, Christina M. Bellon discusses animal experimentation from a feminist perspective.

For the most part, the articles are well-argued and well-structured; they offer subtle and comprehensive analyses and arguments for or against animal experimentation. Given the wide range of topics addressed, I recommend this volume not only to those who desire an introduction to the subject, but also as valuable reading for philosophers and researchers who are well-acquainted with this area of research.

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Simpson, J.R. (ed.): 2012, *Neuroimaging in Forensic Psychiatry: From the Clinic to the Courtroom*. Chichester: Wiley-Blackwell. 397 pp. ISBN 978-0-470-97699-9. Price: £79.99.

In the past few years, there has been a significant expansion in the technological ability to visualize the structure and the functioning of the human brain. Even if neuroimaging still has little place in everyday clinical practice in psychiatry, many researchers predict that it will soon be used to diagnose psychiatric conditions, as well as to predict patient’s responses to treatments. As neuroimaging enters the field of clinical psychiatry, its use in the legal proceedings is becoming more frequent. Neuroimaging methods are already being used in courts and their possible applications are increasing. The need to develop forensic evaluation techniques that are more informed by biological and subjective criteria is discussed more than ever and the field of forensic psychiatry is approaching a crossroads.

The book under review aims to map the field and examine the current and future uses of neuroimaging methods in forensic psychiatry. The volume editor, Joseph R. Simpson, is a Clinical Assistant Professor of Psychiatry at the University of Southern California and the University

of California, Irvine. His PhD thesis work focused on neuroimaging in mood disorders and the functional neuroimaging of cognition-emotion interactions.

The first chapter provides an introduction to neuroimaging technologies. After explaining the methodology and basic function of PET, SPECT, structural and functional MRI, it presents their clinical and forensic uses as well as their limitations. The second chapter reviews the possibilities of neuroimaging techniques for the diagnosis of some psychiatric conditions, such as traumatic brain injury, dementia, psychopathy, antisocial personality disorder, paedophilia, psychosis and affective disorders. The chapter refers to some methodological and technical issues of these techniques, and discusses their forensic application.

The following chapter brings us to the courtroom, aiming to explore the extent to which neuroimaging evidence can assist judges and juries in answering some crucial legal questions, which cover a broad field of criminal law: the competence to stand trial, the definition of legal insanity, diminished capacity defenses, acceptability of neuroscientific evidence in courts and mitigation. Moreover, the chapter discusses the implications of neuroimaging for dangerousness assessments and the treatment of mentally ill offenders and examines its potential uses in personal injury civil cases.

The fourth chapter reviews some of the latest proposed issues of neuroimaging, i.e., “lie detection” and the use of neuroimaging to identify memories, which are fields of

growing importance and of major relevance to forensic uses.

Part V (chapters 15–19) deals with the broader ethical and legal concerns raised by neuroimaging advances. It examines the admissibility, as well as the constitutional perspective of the use of neuroimaging evidence in U.S. courts, including a chapter with reference to the law in England and Wales. After discussing some of the ethical issues that arise from the forensic use of neuroimaging, such as privacy, informed consent, and the prediction of criminal behavior, the book ends with a chapter on the methodological and legal limitations of neuroimaging in the courtroom, pointing out the need for scientific modesty and for genuine legal relevance.

By providing a practical account of the current and future applications of neuroimaging in forensic mental health, this volume comes to cover the gap in the existing literature on Neuroscience and Law, which is mainly focused on the path from the lab to the courtroom, largely disregarding the forensic psychiatrists’ perspective. By making a careful evaluation of the existing forensic uses of neuroimaging techniques, this book proves to be a useful tool for forensic psychiatrists and psychologists, as well as for legal practitioners, attorneys and judges helping them to navigate in this new area of increasing interest.

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